

## **Appendix A. Example Concept Elicitation Interview Guides**

A1. Patients

A2. Experts

# A1. EXAMPLE PATIENT CONCEPT ELICITATION INTERVIEW GUIDE

PARTICIPANT ID: \_\_\_\_\_

DATE: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (MM/DD/YY)

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## I. INTRODUCTION

### A. Interviewer Introduction

Hello. My name is [Name]. Thank you for agreeing to do this interview with me today.

### B. Purpose and Procedures

Thank you for taking the time to talk to me today. As you know, you were invited to participate in this study because you have been diagnosed with amyloidosis. We are conducting several interviews with patients with amyloidosis to learn more about the issues that you face and how these issues affect your life. We recognize that this experience may vary from person to person, and we are interested in the full range of experiences you have had. The information that you provide will help us design better patient questionnaires for patients with amyloidosis.

My role during the next hour is to ask you questions. There are no right or wrong answers to the questions. If at any time during our discussion you do not feel comfortable answering a question, that is fine. You do not need to talk about anything you do not feel comfortable talking about. If you want to take a break or stop, just let me know. This area has not been researched much and you are the expert.

We are recording this conversation so that we can listen to it again later if we need to. When the study is over, we will destroy the recording. If it is ok, I will start the recorder. [START RECORDER.]

Do you have any questions for me before we begin?

### C. Participant Introduction/ Warm-Up

To get started, I'd like to learn a little more about you.

1. When were you diagnosed with amyloidosis?
  - a. Tell me more about that.
2. Have you ever had the opportunity to talk with anyone about how your health affects your life?

## II. CONCEPT ELICITATION

### A. Scope and Importance [Goal: to understand the scope and importance of the topic]

First, the researchers are interested in hearing about how amyloidosis and treatments for amyloidosis can affect how patients feel and function.

1. How has your body felt over the past seven days?
2. Have you had any changes in your body?
3. Have you had any changes in your body that maybe surprised you or that you didn't expect?
4. How have your feelings been in the past seven days?
5. Is this an important topic?
6. How does amyloidosis affect your life?

## A1. EXAMPLE PATIENT CONCEPT ELICITATION INTERVIEW GUIDE

### B. Specific Symptoms and Impact [Goal: to understand symptoms and functioning]

1. Let's talk specifically about symptoms. How does amyloidosis or its treatments affect how you feel?
2. Can you describe all of the different symptoms that you experience? [Probe for physical, emotional, and social factors, and for each one named ask:]
  - A. How did [symptom] begin?
  - B. What did you first notice?
  - C. How much does [symptom] bother you?
  - D. Do you have any fears or concerns about [symptom]?
  - E. What makes [symptom] worse?
  - F. What makes [symptom] better?
  - G. Have you ever talked to your doctor or someone else on your health care team about [symptom]?
3. I want you to think about all the things you do in your life. How does amyloidosis or its treatments affect what you can do in your life?
  - A. What are some things you don't do now that you normally would be able to do?
  - B. Is there anything you do now that you didn't normally do before?

### III. WRAP-UP AND THANK YOU

Interviewer should review the landscape of what was discussed.

1. Is there anything else that you think would be helpful for the researchers to know about?
2. When you think about the issues we discussed, which ones are most important to you?
3. How significant are these changes compared to other important issues or priorities in your life?

**Thank you for participating in this study!**

## A2. EXAMPLE EXPERT CONCEPT ELICITATION INTERVIEW GUIDE

PARTICIPANT ID: \_\_\_\_\_

DATE: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (MM/DD/YY)

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### I. INTRODUCTION

#### A. Interviewer Introduction

Hello. My name is [Name]. Thank you for agreeing to do this interview with me today.

#### B. Purpose and Procedures

Thank you for taking the time to talk to me today. We are conducting several interviews with clinicians to learn more about the issues that patients with amyloidosis face. The researchers are interested in creating a patient-reported measurement tool that is relevant to patients with AL. Thus, we are specifically interested in knowing your thoughts about the most important symptoms experienced by these patients. There are no right or wrong answers to the questions that I ask you. If at any time you do not feel comfortable answering a question, just let me know. We are recording this conversation to facilitate analysis. When the study is over, we will destroy the recording. If it is ok, I will start the recorder. [START RECORDER.] Do you have any questions for me before we begin?

#### C. Participant Introduction/ Warm-Up

To get started, I'd like to learn a little more about you.

1. What is your specialty?
2. How many years have you been in practice?
3. Can you tell me about your experience taking care of patients with amyloidosis?
4. How many patients with amyloidosis do you treat?
5. Do you conduct research that includes patient-reported outcome measures?
  - a. Tell me more about that.
  - b. What measures have you used?
  - c. Is there anything that could improve on currently available measures?

### II. CONCEPT ELICITATION

#### A. Scope [Goal: to understand the scope and importance of the topic]

1. What do you think are the most important symptoms of patients with amyloidosis?
2. What other symptoms do patients with amyloidosis experience?
3. How do symptoms affect patients' lives?
4. Probe for physical, emotional, and social factors, and for each ask about the:
  - a. Intensity/severity of [symptom] (How strong is it?)
  - b. Frequency of [symptom] (How often does it happen?)
  - c. Duration of [symptom] (How long does it last?)

## A2. EXAMPLE EXPERT CONCEPT ELICITATION INTERVIEW GUIDE

- d. Unpredictability of [symptom] (How easily can it be anticipated?)
  - e. Variability of [symptom] (How much it fluctuates over time?)
5. What about any other concerns that patients have?

### III. WRAP-UP AND THANK YOU

Interviewer should review the landscape of what was discussed.

1. Is there anything else that you think would be helpful for the researchers to know about?

**Thank you for participating in this study.**